8-5-2017

Implementing an Online Health Information Platform for People With Serious Mental Illness

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Introduction: Individuals with serious mental illness (SMI) die, on average, 25 years earlier than the general population. Higher rates of smoking, alcohol consumption, poor nutrition, lack of physical activity, obesity, lack of preventive healthcare, and other modifiable risk factors, as well as side effects associated with certain antipsychotic medications, place individuals with SMI at high physical health risk. They are designated a health disparity population by the US National Association of State Mental Health Program Directors and as a vulnerable group worldwide by the World Health Organization. While the Internet provides intriguing opportunities to support person-centered health care, web-based resources often convey new barriers and consequently, contribute to greater health disparities for individuals with SMI. Many individuals with disabilities or a chronic illness, report feeling frustrated, overwhelmed, and confused using the Internet. Web design accommodations for this population have been recommended, but not generally applied.

Results From Focus Groups:

1. **Sources of Information Health**
   ➢ Google search
   ➢ Specific websites (WebMD, Patients like me)
   ➢ Social media
   ➢ Physicians/therapists
   ➢ Other: pharmacists, peers, self-help books, libraries, magazines, online support groups

FOCUS GROUP PARTICIPANTS - AGE
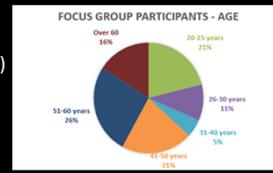
2. **Criteria for Choosing the Right Website**
   ➢ *Professional* websites: comprehensive content or focus on symptomatology
   ➢ *Forums:* where there is a specific information about *me*
   ➢ Criteria for identifying a website as "Professional"
     ✓ Having an authority name: National Institute of Mental Health, name of university
     ✓ Websites that sound familiar and/or include the name of the own diagnosis: WebMD, Brain Care Institute, Wikipedia

3. **Top Searched Information Topics/Patient Knowledge Needs**
   ➢ Medications: side effects and interaction
   ➢ Practical tips and coping skills (i.e. how to function in life while having a mental condition)
   ➢ Physical and Mental health
   ➢ Prevention (diet)
   ➢ Interactivity

HOW WELL DO YOU KNOW HOW TO SEARCH THE WEB USING KEYWORDS
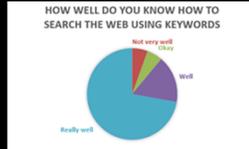
4. **The *Perfect* Website**
   ➢ Characteristics of a 'good' website
   ➢ *Technical* characteristics (easy navigation, comprehensive language, etc.)
   ➢ *Content* characteristics (holistic information)
   ➢ Online interactivity (online support groups, chats, forums)
   ➢ Challenges for people with SMI to consider in creating the website (cognitive problems, no internet access from psychiatric hospitals)

5. **Need for Holistic Information**
   ➢ Need for *holistic* information
   ➢ Layout and technical features: using graphs, alive colors, videos
   ➢ Accommodations for disabilities (dyslexia)
   ➢ Tone: avoid stigmatizing and labeling
   ➢ Creating an own personal account , possibly to share with their therapist before sessions

Methods: Phase one of this three-year project focused on an environmental scan of available resources and needs assessment. We conducted six IRB-approved focus groups (n=42) with individuals with SMI and with health information providers (librarians, researchers and practitioners) with the goal of embracing user experience and design accommodations required for individuals with SMI.

Conclusion: Through the results of the focus groups, we identified central themes regarding the general usage of online resources among people with SMI (e.g., types of online sources used, criteria for choosing the appropriate website, types of information searched) as well as themes identifying the specific needs and requirements that this population have in gathering information (e.g., the need for holistic information, suggestions for coping skills, content encouraging hope, and language that avoids labeling and stigma)). We can conclude that people with SMI lack literacy skills on how to appropriately select and use online health information. There is a need for online tools providing holistic information about how to manage physical and mental health.

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"I feel like for me there's two layers to it. I really want official information if I'm looking up the clinical side effects, I want to look for a really research-heavy website or like, a WebMD that I recognize and am familiar with. But if I'm looking up, like, side effects of a medication, I want to hear from the people on the actual medication. I don't want professional resources as much, I more want to hear from peers who are using that."

"I want to know more about how to manage my symptoms during the day, what coping strategies I can use to deal with my problems while going through school, work and life in general."

"The first thing that I want to know is the interaction between all the medications that I am taking, this is the first thing that I check!"

"I want to see online things that can bring my joy like recipes, nice images and not only focusing on problems."

Image: http://www.mkiellinikou.org

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